Macular Society
Beating Macular Disease

Visual hallucinations

Some people with sight loss experience visual hallucinations. Many worry unnecessarily about the cause of these.

This leaflet is available on audio CD.

You don't have to face macular disease alone. For the best information and support call us on 0300 3030 111.

Hallucinations can occur as a result of sight loss.

Up to half of all people with macular degeneration are thought to experience visual hallucinations at some time.

They are more likely to occur if both eyes are affected by sight loss but can occur with problems in one eye only. The hallucinations often start after a sudden worsening of vision.

When hallucinations happen as a result of sight loss, they are known as Charles Bonnet syndrome (CBS), after an 18th century Swiss scientist and philosopher who first described the condition. Charles Bonnet hallucinations are not a sign of mental illness.

What is a visual hallucination?

A visual hallucination is the same experience as really seeing something, but the 'something' is not actually there.

Visual hallucinations appear to exist in the real world rather than in the mind's eye. They come and go unannounced and can last for just a few seconds or as long as a day or more.

The syndrome itself can last from days to many years. For most people the hallucinations improve with time so that they only occur very occasionally.

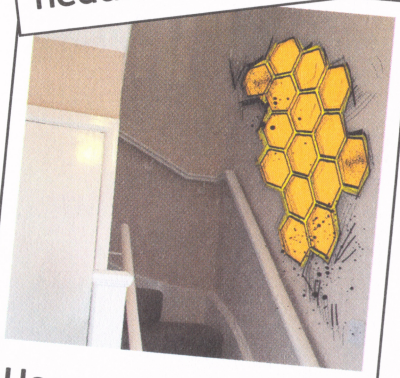
What do these hallucinations look like?

Charles Bonnet hallucinations can be simple unformed flashes of light, colours or shapes. However, many people see more elaborate forms such as geometrical grids and lattices.

Some people report seeing landscaped gardens or vistas, animals, people, or processions of miniature costumed figures wearing hats, or even disembodied faces with staring eyes.

For example:

Floating gargoyle heads



Honeycomb patterns on the wall

The hallucinations are often seen in more vivid detail than real life. Some people enjoy their hallucinations. However, they are more often an unwanted distraction and can be frightening.

They can get in the way of normal vision too.

Can you stop the hallucinations?

The Macular Society has sponsored research by Dr Dominic ffytche at King's College London to look into ways of stopping hallucinations when they occur.

Dr ffytche recommends using eye movements to lessen the impact and length of hallucinations.

Eye movements activate visual parts of the brain in people with macular disease – even if they have little remaining vision.

These movements may stop certain types of hallucinations, particularly the patterns and colours.

When a hallucination appears try the following exercise:

- Imagine two points about a metre (3ft) apart left and right on a wall in front of you.

Stand about a metre and a half away and look from one point to the other once every second or faster for 15–30 seconds. Don't move your head and keep your eyes open when looking left and right. Have a break of a few seconds.

- If your hallucinations are still there, try repeating the exercise. If they have not stopped after four or five attempts, the technique is unlikely to work. You may however want to try again on another occasion or for a different type of hallucination.

Other ways to stop a hallucination

- Shut your eyes or look away from the image.
- Switch on the room lights or, if in a brightly lit area, move somewhere darker.
- Simply get up and do something else.

This can cause the hallucinations to disappear; however, they often continue.

Other treatments for hallucinations

Stopping hallucinations when they occur works for some people but others need more help.

There are treatments available now and being developed.

Some medications can help people with very distressing hallucinations. These medications are usually prescribed for other conditions but have been shown to work for Charles Bonnet hallucinations. It would usually require a specialist doctor to prescribe them and further tests to see if they are safe to use and to rule out other causes of hallucinations.

Developing new treatments for hallucinations is important. The Macular Society has sponsored research led by Professor John-Paul Taylor at Newcastle University to investigate whether using a mild electric current on the scalp at the back of the head can stop visual hallucinations. The technique is called 'transcranial direct current stimulation' (tDCS).

Preliminary findings suggest it is helpful in reducing the number of hallucinations experienced and there are few, if any, side-effects but further research is needed to confirm this.

Why do the hallucinations happen?

When visual signals leave the eye they go to the back of the brain (the occipital lobe) to the primary visual receiving area.

From here the signals are relayed to a series of map-like areas, each specialised in a different aspect of seeing. There is an area specialised for movement, an area for colour, several for faces, one for landscapes and many others.

Scanning studies have revealed what happens in the brains of people while they hallucinate. These studies help explain some of the features of Charles Bonnet hallucinations.

With our eyes open, the visual brain expects to receive and process a flood of complex electrical signals. In people with eye disease or a break in the visual pathways, what was once a flood becomes a trickle. This leaves the visual areas of the brain with little to do.

The idle visual brain cells, waiting for an appropriate trigger, begin to fire spontaneously.

If this happens in the colour area, people experience hallucinations of colour; if in the object area, they see objects and so on.

After a while, the visual brain gets used to the lower level of information from the eye and the spontaneous firing lessens or stops.

This explains why, for many people, the hallucinations gradually reduce over time.

What do we still need to know?

More research into Charles Bonnet syndrome is needed. For example, we do not know why only some people with sight loss have hallucinations. Research funded by the Macular Society is helping answer this question but more is needed.

One thing that is certain is that hallucinations do not mean the person is mentally ill.

However bizarre, frightening or funny their content, Charles Bonnet hallucinations are no more than a normal brain's response to reduced visual input. While they may be an inconvenience, they are not a cause for concern.

If you find your hallucinations upsetting, talk to your doctor or ophthalmologist about the problem.

Take this leaflet with you as some health professionals outside the eye specialty may not know about Charles Bonnet syndrome.

These characteristics might suggest that there are conditions contributing to the hallucinations other than Charles Bonnet syndrome:

- voices and visions
- hallucinations only of people and animals, without hallucinations of patterns, colours, shapes and lines
- elaborate explanations
- calling police or ambulance
- Forgetting the hallucinations are unreal at the time they occur
- confusion / memory concerns
- accompanying person more aware of the hallucinations than the patient.

With thanks to Dr Dominic ffytche, King's College, London

For research references visit **macularsociety.org/references**

What support is there?

The Macular Society runs a CBS support group via our counselling service.

This is done over the telephone and you can speak to other people experiencing CBS as well as one of our professional counsellors. If this is something that could help, you can either call the Advice and Information Service on 0300 3030 111 to complete the referral form or complete it online: **macularsociety.org/support/counselling**

Beating Macular Disease

Macular disease is the biggest cause of sight loss in the UK, with around 300 people diagnosed every day.

The Macular Society is the only charity determined to beat the fear and isolation of macular disease with world-class research, and the best advice and support.

To support people affected by macular disease now, the Macular Society provides a range of support, information and services:

The **Advice and Information Service (0300 3030 111).** Available Monday to Friday, 9am to 5pm. Alternatively, you can email help@macularsociety.org Our website at **macularsociety.org** provides a wide range of information and resources for people affected by macular disease.

Our network of over 400 **Macular Society Support Groups** across the UK. Each one offers practical and emotional support for people with macular disease, from those living with it today.

Our free, confidential **Counselling Service**, which offers support over the phone from one of our trained counsellors. You can also call our Advice and Information Service for more information and to be referred for counselling.

Our **Telephone Befriending Service**, which pairs you up for regular telephone calls with another person with macular disease who knows what it is like to live with the condition. Calls can be about anything, and provide friendly support.

Working with you to Beat Macular Disease:

- We provide the best advice and information on living with macular disease.
- Macular Society Support Groups can help you to beat the isolation of macular disease, by connecting you with other local people who know what you're going through – offering support and companionship.
- Our research programme is focused on finding new treatments and a cure to Beat Macular Disease forever.

Macular Society

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